



Published in final edited form as:

J Dev Behav Pediatr. 2015 October ; 36(8): 575–585. doi:10.1097/DBP.0000000000000205.

Examining Parents' Experiences and Information Needs Regarding Early Identification of Developmental Delays: Qualitative Research to Inform a Public Health Campaign

Melissa Raspa, PhD^{*}, Denise M. Levis, PhD[†], Julia Kish-Doto, PhD^{*}, Ina Wallace, PhD^{*}, Catherine Rice, PhD[†], Brian Barger, PhD^{†,‡}, Katie K. Green, MPH[†], and Rebecca B. Wolf, MA[†]

^{*}RTI International, Research Triangle Park, NC

[†]National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

[‡]Disability Research and Dissemination Center, University of South Carolina, Columbia, SC

Abstract

Objective—The purpose of this study was to assess the approach and materials of Centers for Disease Control and Prevention's “Learn the Signs. Act Early.” (LTSAE) health education campaign, which aims to improve awareness of developmental milestones and early warning signs of developmental delay among parents of young children.

Methods—We conducted 2 phases of qualitative research. Focus groups assessed the campaign's objectives by exploring the experiences of parents with children who have developmental delays or disabilities to determine facilitators of and barriers to identification. In-depth interviews were conducted with parents of typically developing children, who reviewed campaign materials and provided feedback on appropriateness, appeal, and clarity with regard to the campaign's objectives.

Results—Phase 1: Parents were typically the first to express concern about their child's development, and most talked with their child's health care provider. Two categories of health care providers emerged: those who proactively asked about a child's development, used tools to facilitate conversations, and made referrals, and those who did not ask about development, told parents to “wait and see,” and did not provide information about services and supports. Few parents knew about special education services before identification. Phase 2: Participants found the campaign materials appealing, but were unclear about how to act early and why acting early was important.

Conclusions—Results affirmed LTSAE's evidence-based approach to educating parents about child development. Additional campaign considerations include providing more information about how to act early and why acting early is important and enhancing outreach to providers to help them communicate with concerned parents.

Address for reprints: Melissa Raspa, PhD, 3040 Cornwallis Rd, Research Triangle Park, NC 27709; mraspa@rti.org.

Disclosure: The authors declare no conflict of interest.

Index terms

early identification; developmental delay or disability; parental concerns; qualitative research; health education campaign

Early identification of infants and toddlers who are delayed in meeting key developmental milestones is critical to improving the likelihood that they receive appropriate services and supports at the earliest age possible. The goal of such services and supports was to enhance children's functioning and reduce the potential for long-term disability.¹ Intervening early can provide short-term and long-term benefits for both children and their families.^{2,3} Estimates of developmental disabilities among children vary from 3.5% to 15%.⁴⁻⁶ However, data indicate that only 2.8% of the population of infants and toddlers receive early intervention services, such as speech-language therapy, through Part C of the Individuals with Disabilities Education Act.⁷ These data suggest that a significant number of young children may not be identified as early as possible. In fact, nearly half of all children with developmental disabilities are not identified until they enter Part B school-aged services, and therefore are not able to participate in early intervention services.⁸ This article describes 2 phases of qualitative research undertaken to assess appropriateness and acceptability of a public health campaign that seeks to facilitate early identification.

Key professional organizations maintain that pediatricians should play an important role in helping to identify developmental delays by monitoring milestones and conducting routine developmental screenings during well-child checkups.⁹⁻¹² The American Academy of Pediatrics (AAP), in collaboration with other partners, developed a national health promotion initiative called *Bright Futures*, which aims to help pediatricians take a more active role in prevention and health promotion.¹³ Moreover, AAP's 2006 policy guidelines stress the importance of developmental surveillance, or monitoring, which includes eliciting and attending to parental concerns about their child's development.¹⁴ A recent survey of pediatricians conducted by the AAP found that approximately 48% of pediatricians used a standardized developmental screening tool.¹⁵ These recommendations recognize that parents are often the first individuals concerned about their child's health, behavior, and development.¹⁶ Research consistently shows that a parent's concerns about a child's development and behavior are often valid and, when heeded, can promote early identification.^{8,17}

Parent-Provider Communication

Early work has shown an under-identification of potential developmental problems because of the lack of discussion about, or attention to, parents' concerns.¹⁸ One study showed that approximately one-third of parents with concerns did not discuss them with their child's health care provider, and race/ethnicity, level of education, employment status, marital status, or number of children in the home were not predictive of whether parents raised developmental concerns.¹⁹ Parents who shared concerns with their child's health care provider mainly discussed expressive language or general health issues. The study found that, in general, children whose parents communicated developmental concerns were 4 times

more likely to be enrolled in early intervention than children whose parents did not share concerns with a provider.

Data show the importance of communication between parents and providers about developmental concerns and the need for both groups to attend to differing communication styles when discussing development.²⁰ Concerned parents may be direct with their concerns or may express concerns subtly, such as asking about the expected age for a specific milestone. Parents who discussed developmental concerns with providers indicated that it was important to them that their provider was supportive and took their concerns seriously. Many parents had negative opinions about provider responses such as “wait and see” or “your child will grow out of it.” Moreover, this is not in keeping with the AAP policy guidance on following up on parental concerns with a formal screening regardless of whether it is at a specified checkpoint.¹⁴ Preference for a provider's communication style, when discussing concerns, differed among parents. Some appreciated honest, straightforward discussion of concerns and possible issues, whereas other parents, who needed more time to prepare for a diagnosis, seemed to prefer non-alarmist responses and provision of resources that could set the stage for future discussions about development.

Results from the 2011-2012 National Survey of Children's Health show that approximately 40% of parents of young children reported having 1 or more concerns about their child's development.²¹ Strategies to facilitate communication between parents and their child's provider could be helpful in determining when a parent needs guidance for a resolvable concern and when further screening or evaluation is needed. Studies examining interventions aimed at improving parent-provider communication through the use of standardized screening tools show that providers perceive such tools as useful for guiding conversations with parents, encouraging more patient-centered practices, allowing for more information exchange, and enabling parents to raise concerns more frequently.^{22,23}

“Learn the Signs. Act Early.” Campaign

Centers for Disease Control and Prevention's “Learn the Signs. Act Early.” (LTSAE) program aims to improve early identification of children with autism and other developmental disabilities so children and families can get the services and support they need. The LTSAE health education campaign focuses on helping parents of all young children improve their awareness of developmental milestones and early warning signs of delay. The campaign's key communication objectives are to (1) increase knowledge of developmental milestones and the importance of tracking a child's development, (2) promote communication between parents and health care providers about milestones, and (3) motivate parents to act early if there are concerns about a child's development by asking their child's health care provider about developmental screening and/or contacting their local early intervention program for a multidisciplinary evaluation.²⁴

The campaign has developed a suite of health education materials for parents as well as health care providers and early educators, including single-age milestone checklists, milestone products featuring a range of ages (e.g., brochure, booklet), a children's book for 3-year-olds, growth chart, campaign flyers, and single-page fact sheets covering a number of

topics including tips for sharing concerns about development with a health care provider and tips for talking with parents about concerns (for early care and education providers). Materials can be accessed at www.cdc.gov/ncbddd/actearly.

Using behavior change theory and traditional social marketing techniques, LTSAE was originally conceived as a health education campaign to increase awareness of autism spectrum disorders (ASD). However, early campaign development research conducted with parents and health care providers and national survey data analysis revealed that many parents were aware of ASD, but they did not know the developmental milestones they should be monitoring or the early warning signs of ASD, nor did they believe that autism was relevant to them.²⁵ Parents who were interviewed also said that they preferred a campaign that educated all parents about developmental monitoring over an autism-specific campaign, which many felt would be unappealing and unsettling (P. Novelli, unpublished data, February 2004). From this research, the current approach of LTSAE took shape.

Purpose

The purpose of this study was to formally reassess the appropriateness of the LTSAE communication approach, which encourages parents to take an active role in monitoring and tracking their children's developmental milestones during early childhood and acting early if there are concerns. To accomplish this, we conducted 2 phases of qualitative research. In Phase 1, we conducted focus groups with parents of children who have developmental delays or disabilities to explore parents' experiences in getting their children identified, including the kinds of information that facilitated identification and what barriers they may have faced. In Phase 2, we conducted in-depth interviews with parents of typically developing young children to gather feedback on current LTSAE materials to determine appropriateness, appeal, and clarity with regard to LTSAE's learning and communication objectives and when best to receive materials. Findings will be used to improve the campaign's communication objectives, messages, materials, and dissemination strategies.

Methods

Participants

We partnered with 14 early childhood and parent organizations (e.g., Early Head Start) across 3 states (Colorado, New York, and North Carolina) to recruit parents for Phases 1 and 2. Recruitment partners distributed flyers and screened interested parents to determine eligibility. In Phase 1, focus group parents were recruited who met the following criteria: had a child who was 10 years old or younger who had an identified delay or disability and was currently receiving early intervention or special education services. We did not include parents with children who were identified with a disability at birth or soon after because they likely would have different experiences with identification and navigating the health care system. To align with the “Learn the Signs. Act Early.” (LTSAE) campaign's priority audiences, we focused recruitment efforts on low-income parents and invited both English-speaking and Spanish-speaking parents to participate. To help achieve a diverse sample (Table 1), our recruitment strategy included segmentation based on the participants' race/ethnicity, age of their child, and type of delay or disability, that is, we capped recruitment

once we reached a quota for a given subgroup (e.g., no more than half the participants in a focus group who had a child with autism).

Phase 2 used similar recruitment procedures as Phase 1. Eligibility requirements included parents with a child who had not been referred or evaluated for specialized services or diagnosed with a developmental delay or disability and who, at the time of recruitment, was between 6 months and 4 years old. By limiting the number of participants with older siblings at each site, the sample included a larger proportion of parents with limited experience monitoring children's development. Recruitment focused on low-income parents, both English and Spanish speaking. A diverse group of parents, based on race/ethnicity, age of oldest child, and total number of children, participated (Table 1).

Procedures

We conducted focus groups in Denver and Colorado Springs, Colorado (4 groups, n = 24); New York (Manhattan and Bronx), New York (4 groups, n = 32); and Greensboro and Durham, North Carolina (3 groups, n = 18). Experienced moderators facilitated the focus groups. Six of the 11 focus groups, 2 in each region, were conducted with a native Spanish-speaking moderator and Spanish-speaking participants. Discussions lasted approximately 90 minutes. The groups were digitally recorded and later transcribed for data analysis. Focus groups were selected as the best approach for this phase of the study because they allowed the researchers to gain insights into participants' shared understanding of topic.

Nine months later, we conducted in-depth interviews with parents of typically developing children in Colorado Springs, Colorado (n = 5); New York (Manhattan), New York (n = 10); and Durham, North Carolina (n = 6). We conducted 9 of the 21 interviews in Spanish with native Spanish-speaking participants. Moderating and note-taking procedures were identical to Phase 1 procedures. Interviews lasted approximately 60 minutes and were audiotaped for later transcription and analysis. Interviews were the most appropriate approach for this phase as they ensured that participants were not influenced by what others say.

Measures

The moderator's guides for both phases of research were created with campaign objectives in mind. Phase 1 focus group moderators used a semi-structured guide to facilitate the discussion. The guide was structured around parents' experiences during 3 time periods: (1) First Concerns: The time leading up to when the parent or someone else first became concerned about the child's development (e.g., who first became concerned? when?); (2) Seeking Help: After the parent first became concerned about the child's development but before the child was identified with a delay or disability (e.g., whom did you talk to about your concerns?); and (3) Starting Services: After the child was identified, when the parent began seeking services and supports (e.g., how long after first concerns did your child get help?). Moderators also asked parents about which informational resources they used and whether additional information would have been helpful.

Phase 2 in-depth interviews included semi-structured questions to guide discussion around 4 LTSAE materials: (1) the Milestones checklist (age specific), (2) the Milestones information card (age specific), (3) the Milestones brochure, and (4) the Milestone Moments booklet

(Fig. 1). The questions focused on the following: (1) intended audience and appeal, (2) purpose and clarity of campaign messages, and (3) placement and timing of materials delivery.

Data Analysis

Data were analyzed using NVivo v.10.0 qualitative software.²⁶ Text from the transcripts were coded using an inductive approach to content analysis.²⁷ Using the questions outlined in the moderator guides, we created categories to begin organizing the data. Next, we reviewed each transcript and began coding. To establish consistency in coding, 3 reviewers independently coded 3 transcripts, which were then reviewed and discussed. Minor modifications were made to ensure there was more than 80% agreement on codes. The reviewers then independently coded the remaining transcripts. Next, 2 additional team members reviewed the codes and organized the data into common themes. This approach was used for both the focus group and interview data.

Ethical Considerations

This study received approval from RTI International's Institutional Review Board. All parents signed a written consent form before the start of the focus group or interview. Identifying information was collected for recruitment purposes only and was not used in data analysis; we did not link names to the results. As a token of appreciation for their valuable input, all participants received a cash incentive at the conclusion of data collection.

Results

Phase 1: Focus Group Findings

The following section describes the themes that emerged from the focus groups. Table 2 contains an overview of the themes and illustrative quotations for each.

First Concerns—The focus groups began with a discussion of first concerns by describing who first expressed concern about their child's development, what the concern was, and how old the child was at the time of first concerns. Findings showed that parents were typically first to express concern about their child's development. Less frequently mentioned as initially voicing concern were other family members, friends, or health care providers. Most concerns stemmed from their child having delayed speech or a lack of words altogether. At times, this was coupled with aggression or other behavior problems that parents linked to the child's inability to communicate. Some participants mentioned concerns related to social or physical development. Participants typically reported that their children were between the ages of 1 and 2 years when they first had developmental concerns. Some parents reported concerns as early as 7 months and others as late as 3 years. Many parents compared their child's development with children of the same age to determine if their child was developing differently. A few participants mentioned that they were first-time parents, which made it challenging to know what to expect of their child developmentally. Not surprisingly, many parents recalled experiencing a powerful range of emotions when relating their first concerns about their child's development, including denial and depression.

Seeking Help—Next, participants described what they did after the developmental concerns first were identified, including to whom they talked and, if applicable, how long they waited to see a health care provider or other professional and how health care providers responded to their concerns. Most participants talked with their child's primary health care provider about their concerns. However, a few participants talked with a specialist first and a few raised concerns with their child's teacher (e.g., child care or preschool teacher). Among those who talked with their primary health care providers, responsiveness to participants' concerns varied. Two categories of health care providers emerged from these discussions. The first category of health care providers were facilitators, who often proactively asked about the child's development and progress, had parents complete questionnaires at each visit, and, when a concern was noted, acted quickly to refer the child and family to a specialist for early intervention. The second category of health care providers, however, did not discuss the child's development regularly with parents, were more likely to say “wait and see” when the parent expressed a concern, and infrequently provided information on early intervention or where to seek additional support. When participants encountered a monitor who told them to wait and see, they had a variety of reactions. Some parents changed providers. Others persisted and asked their provider for help or a referral. Only a few parents mentioned waiting before raising their concerns again.

Starting Services—Participants also discussed their experiences with starting services, many of whom reported that their child became eligible for early intervention or preschool special education and began receiving services shortly afterward. This was most often the case for children with autism or severe speech delays. Some participants reported delays in receiving a referral and/or services although they repeatedly reported concerns about their child's development to their health care provider. This was especially true for parents of children with speech delays. The length of time that providers waited to offer a referral to services ranged from 1 to 7 months. Only a few parents knew about early intervention or school services before their child's developmental delay being identified; these participants knew about it from personal experience (e.g., another family member had a disability or developmental delay) or from media outlets (e.g., commercials, magazines, and pamphlets).

Resources—Participants said that they used a variety of resources when trying to understand their child's development, including Internet searches, books, the library, or calling a hotline (e.g., 311). Some received information about child development from their child's preschool before their first concerns, and others said they received information after their child began receiving early intervention services. Participants less frequently mentioned pediatricians, other health care providers, hospitals, or health fairs as sources of information. When asked what other resources would have been helpful, participants provided numerous suggestions, including information on what to expect at different ages (e.g., brochures, flyers, posters) or phone numbers of agencies to contact with questions. When shown a sample “Learn the Signs. Act Early.” Milestones checklist (Fig. 1), all participants thought it would have been helpful to have as an aid when monitoring their child's development. Most participants reported that they valued receiving information about child development from health care providers and teachers at different points of time such as pregnancy, after delivery, and at well-child visits.

Phase 2: In-Depth Interview Findings

Table 3 presents each theme that emerged during the in-depth interviews with parents of young, typically developing children, including descriptive quotations for each.

Intended Audience and Appeal—Participants reviewed the materials and understood that parents of young children were the intended target audience for the materials. Participants also mentioned other groups who would be appropriate recipients of the materials: young or first-time parents, grandparents, and child care providers or teachers. When asked to choose their favorite material, most preferred the Milestone Moments booklet, stating that it was comprehensive, colorful, and user-friendly. Most participants also liked the age-specific Milestone checklist (Fig. 1) although a few thought they looked too clinical.

Purpose and Clarity of Messages—Participants understood that the purpose of materials was to educate parents about milestones and help them to track their child's progress over time. A few said the purpose of the materials was to educate parents about how to identify problems with their child's development.

Participants who thought the materials did a good job of communicating the campaign's "learn the signs" messages stated that the formatting and organization made the purpose and importance of developmental monitoring very clear. Most participants asked to keep the materials after the interview and said that they would consult the milestones regularly. This was particularly true of the Milestone Moments booklet (Fig. 1), which features milestones and suggested activities for encouraging a child's development across a range of ages (2 mo-5 yr).

Efficacy of Materials—Participants were asked to review the 3 messages about acting early in the materials. They preferred the message in the Milestone brochure ("Don't wait. Acting early can make a real difference!"; Fig. 1), over the messages in the information card ("Use this [card] as a guide, and if you have any concerns, talk with your child's doctor and call 1-800-CDC-INFO") or the Milestone Moment booklet and checklist ("Act early by talking to your child's doctor if your child [demonstrates any of the following behaviors]"). Participants suggested that it be used consistently across materials to stress the importance of acting early. When discussing this message further, most participants said that they understood the "early" aspect of the message, but not the "action" component. For example, participants most often said the materials helped them to know that it was important not to wait or ignore symptoms if they noticed something wrong with their child. A few others commented that acting early could prevent the issue from getting worse. However, many participants thought the materials were less clear on how to act early and only a few recalled specific examples of acting early in the materials. Upon further probing, though, most were able to recognize at least 1 way to begin the process of acting early (e.g., talk to child's doctor about concerns, go to LTSAE's web site, or call toll-free hotline).

Some participants thought additional information was needed to fully understand what it meant to "act early." In particular, they thought the materials needed more information about why parents needed to act early on concerns and additional sources of information besides

the CDC 800 number (e.g., telephone numbers of local resources). In addition, many participants wanted more specific information about who to talk to if they were concerned about their child's development. For example, some participants suggested the materials should be personalized with their doctor's name and phone number. Several of the materials do reference contacting a state or local early intervention system or "someone in your community who is familiar with services for young children"; however, most participants agreed that this information was too general and did not provide specific contact information for other professionals who could answer questions about developmental concerns. Finally, a few participants mentioned the "Questions to Ask Your Doctor" section of the Milestones information card (Fig. 1), which they thought was very helpful information for guiding conversations with their child's doctor. Most agreed that this information could be replicated across materials to assist parents in communicating their concerns.

Placement and Timing—Most participants stated that they preferred to receive child development materials during pregnancy. A few preferred receiving the information at birth or shortly after, noting that pregnancy is not an ideal time because women are often more focused on themselves and their pregnancy rather than on what the child will do once he or she is born. Participants also liked the idea of receiving age-specific material just before a child entered the next age milestone, which underscored the importance of tracking developmental milestones and talking to their doctor about any concerns. Overall, participants agreed that the earlier the information was received, the better.

We also asked participants who should distribute the materials and why they would prefer to receive the information from certain sources. About half of the participants mentioned that it would be useful to receive the materials from their obstetrician or at the hospital as part of their birthing packet. Several participants believed it was the responsibility of their child's health care provider to distribute the materials, especially the age-specific resources (e.g., the Milestone checklist). This also reinforced the belief that parents and health care providers should routinely discuss the child's development during well-child visits, review milestones, and discuss any questions or concerns the parent has about their child's development.

Discussion

The aim of this study was to assess the "Learn the Signs. Act Early." (LTSAE) communication objectives and materials, which aim to educate parents about developmental milestones, improve parent-provider communication, and educate parents about the importance of acting early. The findings support the continuation of the campaign's current approach. However, the data show that some modifications may help enhance the materials. Below, we outline recommended changes based on these findings and considerations for other practitioners who promote child development materials.

The first campaign objective is to increase knowledge of developmental milestones and the importance of tracking a child's development. Our findings suggest that parents related to this goal, for example, as they naturally compared their child's development with other children. Many Phase 1 participants, who had children that were identified with delays or

disabilities, said that although they turned to a variety of resources to gather information about their child's development, it would have been helpful to have more specific information about what to expect at different ages before identification of their child's delay. Phase 2 participants, who had typically developing children, said that the materials were easy to understand, appealing to parents, and made it easy to learn more about developmental milestones and track them over time. Findings also provide support for the campaign's focus on outreach to parents with a low socioeconomic background and the usefulness of the materials to this target audience. Although all parents could utilize this information, outreach to parents from low socioeconomic backgrounds is particularly important given that previous research shows that higher levels of parenting knowledge of child development are associated with higher maternal education, income, and age.^{28,29} Developmental surveillance may be of particular importance to vulnerable groups of individuals who do not qualify for early intervention services but may be at risk for developmental delays. Such children and families would still benefit from community-based support, such as home visiting programs.³⁰ More generally, this approach would complement other efforts that aim to promote awareness of child development and early detection of delay, in particular *Birth to 5: Watch me Thrive!*, a new coordinated federal effort focused on advancing developmental screening and supporting families by connecting them to community supports.³¹

Facilitating communication about developmental milestones between parents and their child's health care provider is the second priority of the campaign. Some Phase 1 participants indicated that they were familiar with developmental checklists or questionnaires because their child's provider used them regularly during well-child checkups. These participants reported having an easier time discussing concerns with their providers. This finding is supported by additional studies that show that doctors who use developmental checklists or questionnaires are more likely to ask parents open-ended questions and discuss concerns.^{24,32} However, other participants who raised concerns reported that providers told them to "wait and see" how their child's development progressed and did not frequently provide information about early intervention or other services and supports. Phase 1 findings indicate that LTSAE's materials are an important resource for all parents, some of whom may need supportive information when faced with having difficult conversations with providers. Future iterations of LTSAE materials could be revised to include more information for parents about how to talk to their child's doctor about concerns since this aspect of the Milestones information card was well received by Phase 2 participants.

The final objective of the campaign was to encourage parents to act early on a concern by asking their child's doctor to conduct a formal developmental screening or to seek a multidisciplinary evaluation through their local early intervention program. Phase 2 findings showed that most participants had a hard time identifying the messages about acting early and were not aware of their local early intervention services. When asked to review the 3 messages about acting early that appear in the materials, the majority preferred the following message: "Don't wait. Acting early can make a real difference!" However, participants also said they wanted to know more about why acting early was so important. Findings suggest

that use of a consistent and prominent “act early” message across campaign materials and inclusion of information on local services could strengthen the materials. More information about why parents should act early could also be useful.

These findings should be contextualized with the following limitations. First, due to the qualitative nature of the study and the focus on low-income parents from 3 geographically diverse areas, the results may not be generalizable to the broader population of parents of young children. In addition, the focus group study design of Phase I intentionally involved parents with at least 1 child with a disability to better understand what would have improved the identification of their child's delay. However, this may have introduced bias as these families had to reflect back on the time before their child was identified to answer the research questions. Finally, Phase 2 participants were not asked to review alternate materials in their evaluation, so there may be some degree of social desirability in their responses.

Despite these limitations, the study affirms LTSAE's campaign objectives and materials, which aim to educate parents about developmental milestones, improve parent-provider communication, and educate parents about the importance of acting early. Findings also suggest that LTSAE's current materials could be used to improve parents' awareness of milestones and, with some modification, the importance of acting early.

Pediatricians and others providing primary care for young children can take a central role in this process by using developmental screening tools, monitoring the attainment of young children's developmental milestones, providing parents with tools to facilitate monitoring and conversations about child development, and making referrals when needed. Helping parents understand how to track their child's development and increasing awareness about when and how to talk to pediatricians about their concerns will help to improve the process of developmental monitoring and screening. This, in turn, could lead to earlier identification of children with developmental delays or disabilities so that all children can reach their full potential.

Acknowledgments

This investigation was supported by the Centers for Disease Control and Prevention (Contract 200-2007-20016/020).

References

1. Peacock G, Lin SC. Enhancing early identification and coordination of intervention services for young children with autism spectrum disorders: report from the Act Early Regional Summit Project. *Disabil Health*. 2012; 5:55–59.
2. Guralnick MJ. Why early intervention works: a systems perspective. *Infant Young Child*. 2011; 24:6–28.
3. Hebbeler K, Spiker D, Kahn L. Individuals with Disabilities Education Act's early childhood programs: powerful vision and pesky details. *Top Early Child Spec*. 31:199–207.
4. Simpson GA, Colpe L, Greenspan S. Measuring functional developmental delay in infants and young children: prevalence rates from the NHIS-D. *Paediatr Perinat Epidemiol*. 2003; 17:68–80. [PubMed: 12562474]

5. Rosenberg SA, Zhang D, Robinson CC. Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics*. 2008; 121:e1503–e1509. [PubMed: 18504295]
6. Boyle CA, Boulet S, Schieve LA, et al. Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics*. 2011; 127:1034–1042. [PubMed: 21606152]
7. ECTA Center. [Accessed September 27, 2014] Annual appropriations and number of children served under Part C of IDEA—federal fiscal years 1987-2012 [ECTA web site]. Available at: <http://www.nectac.org/partc/partcdata.asp>
8. Glascoe FP. Evidence-based approach to developmental and behavioural surveillance using parents' concerns. *Child Care Health Dev*. 2000; 26:137–149. [PubMed: 10759753]
9. Earls MF, Hay SS. Setting the stage for success: implementation of developmental and behavioral screening and surveillance in primary care practice—the North Carolina Assuring Better Child Health and Development (ABCD) Project. *Pediatrics*. 2006; 118:e183–e188. [PubMed: 16818532]
10. Pinto-Martin JA, Dunkle M, Earls M, et al. Developmental stages of developmental screening: steps to implementation of a successful program. *Am J Public Health*. 2005; 95:1928–1932. [PubMed: 16195523]
11. Pizur-Barnekow K, Erickson S, Johnston M, et al. Early identification of developmental delays through surveillance, screening, and diagnostic evaluation. *Infant Young Child*. 2012; 23:323–330.
12. Sand N, Silverstein M, Glascoe FP, et al. Pediatrician's reported practices regarding developmental screening: do guidelines work? Do they help? *Pediatrics*. 2005; 116:174–179. [PubMed: 15995049]
13. American Academy of Pediatrics. [Accessed October 1, 2014] Bright futures: health care professionals tools and resources [American academy of pediatrics web site]. Available at <http://brightfutures.aap.org/index.html>
14. Bright Futures Steering Committee & Medical Home Initiatives for Children With Special Needs Project Advisory Committee. Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics*. 2006; 118:405–420. [PubMed: 16818591]
15. Radecki L, Sand-Loud N, O'Connor KG, et al. Trends in the use of standardized tools for developmental screening in early childhood: 2002-2009. *Pediatrics*. 2011; 128:14–19. [PubMed: 21708798]
16. Bailey DB, Hebbeler K, Scarborough A, et al. First experiences with early intervention: a national perspective. *Pediatrics*. 2004; 113:887–896. [PubMed: 15060241]
17. Glascoe FP. Using parents' concerns to detect and address developmental and behavioral problems. *J Spec Pediatr Nurs*. 1999; 4:24–35.
18. Dworkin PH. Detection of behavioral, developmental, and psychosocial problems in pediatric primary care practice. *Curr Opin Pediatr*. 1993; 5:531–536. [PubMed: 7506962]
19. Glascoe FP. The importance of discussing parents' concerns about development. *Ambul Child Health*. 1996; 2:349–356.
20. Sices L, Egbert L, Merver MB. Sugar-coaters and straight talkers: communicating about developmental delays in primary care. *Pediatrics*. 2009; 124:e705–e715. [PubMed: 19752077]
21. National Survey of Children's Health. [Accessed July 30, 2014] NSCH 2011/12 Data query from the child and adolescent health measurement initiative, data resource center for child and adolescent health website. Available at: www.childhealthdata.org
22. Schonwald A, Huntington N, Chan E, et al. Routine developmental screening implemented in urban primary care settings: more evidence of feasibility and effectiveness. *Pediatrics*. 2009; 123:660–668. [PubMed: 19171635]
23. Sices L, Drotar D, Keilman A, et al. Communication about child development during well-child visits: impact of parents' evaluations of developmental status screener with or without an informational video. *Pediatrics*. 2008; 122:e1091–e1099. [PubMed: 18977959]
24. Learn the signs Act early Health education campaign. Centers for Disease Control and Prevention; Available at: <http://www.cdc.gov/ncbddd/actearly/about-health.html> [Accessed June 19, 2015]
25. Daniel KL, Prue C, Taylor MK, et al. “Learn the signs. Act early”: a campaign to help every child reach his or her full potential. *Public Health*. 2009; 123:e11–e16. [PubMed: 19767041]

26. NVivo qualitative data analysis software Version 10. Doncaster, Victoria, Australia: QSR International Pty Ltd; 2012.
27. Thomas DR. A general inductive approach for analyzing qualitative evaluation data. *Am J Eval.* 2006; 27:237–246.
28. Benasich A, Brooks-Gunn J. Maternal attitudes and knowledge of child-rearing: associations with family and child outcomes. *Child Dev.* 1996; 67:1186–1205. [PubMed: 8706517]
29. Bornstein, MH.; Cote, LR. Knowledge of child development and family interactions among immigrants to America: perspectives from developmental science. In: Lansford, JE.; Deater-Deckard, K.; Bornstein, MH., editors. *Immigrant Families in Contemporary Society.* New York, NY: Guilford Press; 2007. p. 121-136.
30. The maternal, infant, and early childhood home visiting program Partnering with parents to help children succeed. U.S. Department of Health and Human Services; Available at: https://www.acf.hhs.gov/sites/default/files/ecd/home_visiting_issue_brief_2015.pdf [Accessed June 19, 2015]
31. Birth to 5: watch Me thrive!. U.S. Department of Health and Human Services; Available at: <http://www.acf.hhs.gov/programs/ecd/child-health-development/watch-me-thrive> [Accessed June 19, 2015]
32. Norlin C, Crawford MA, Bell CT, et al. Delivery of well-child care: a look inside the door. *Acad Pediatr.* 2011; 11:18–26. [PubMed: 21272820]

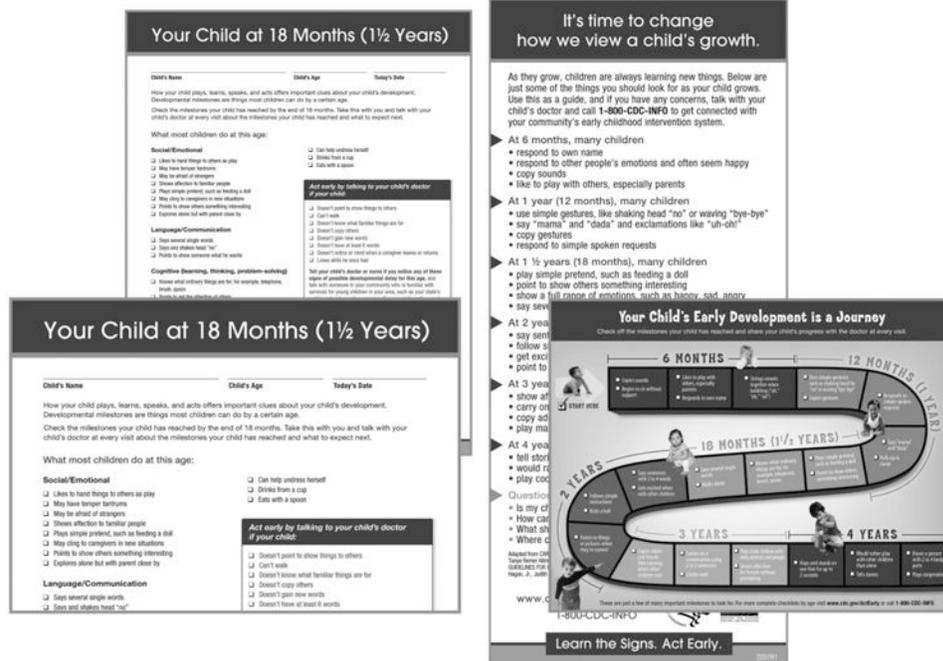


Figure 1. Sample materials for “Learn the Signs. Act Early.” campaign, including (starting upper left, clockwise) milestone checklist, information card, milestone brochure, and Milestone Moments booklet. Materials can be accessed at www.cdc.gov/ncbddd/ActEarly.²⁴

Table 1
Participant Characteristics in Phases 1 (Focus Groups) and 2 (In-Depth Interviews)

	Focus Group Participants (n = 74), n (%)	In-Depth Interview Participants (n = 21), n (%)
Sex		
Male	3 (4)	5 (24)
Female	68 (92)	16 (76)
Age, yr		
18–29	18 (24)	11 (52)
30–35	26 (35)	7 (33)
>35	30 (41)	3 (14)
Race/ethnicity		
Black or African-American	13 (18)	5 (24)
Hispanic or Latino	25 (34)	14 (67)
White	21 (28)	2 (10)
Other	7 (10)	0 (0)
Missing	8 (11)	0 (0)
Income		
<\$30,000	57 (77)	18 (86)
\$30,000–\$39,999	10 (15)	3 (14)
\$40,000	6 (8)	0 (0)
Missing	1 (1)	0 (0)
Child's delay or disability		
Speech/language	42 (57)	NA
Physical	9 (12)	NA
Other (e.g., autism)	18 (24)	NA
Missing	5 (7)	NA
Age of child at identification/diagnosis		
Between 6 and 12 mo	17 (23)	NA
1–2 yr	42 (57)	NA
3–5 yr	2 (3)	NA
5+ yr	5 (7)	NA
Missing	8 (11)	NA
Number of children with developmental delay		
1	41 (55)	NA
2	23 (31)	NA
3 or more	9 (12)	NA
Missing	1 (1)	NA
Total number of children		
1	NA	10 (48)
2	NA	7 (33)
3 or more	NA	4 (19)
Age of oldest child	NA	

	Focus Group Participants (n = 74), n (%)	In-Depth Interview Participants (n = 21), n (%)
Less than 2 yr	NA	5 (24)
2–3 yr	NA	8 (38)
Older than 3 yr	NA	8 (38)

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 2
Focus Group Themes and Select Quotations

Theme	Sample Quotation
First concerns	
Who was first concerned	<p>“I was the first one [to notice] for both my kids.” (CO—English)</p> <p>“In my case, it was the pediatrician who expressed concern....” (NY—Spanish)</p>
Type of concern	<p>“[My child] just wasn't talking at all.” (NY—English)</p> <p>“And lack of, just lack, not really wanting to be social or kind of just not playing with toys.”(CO—English)</p>
Age of concern	<p>“Well for [my son], I knew like around 7 or 8 mo.” (NY—English)</p> <p>“My son was 15 mo old when I started having concerns.” (CO—English)</p> <p>“[My child] was 3 yr old.” (NY—Spanish)</p>
First concerns	<p>“So it was really hard to say, ‘Are my concerns valid or am I just expecting him to follow suit with his brother?’” (CO—English)</p> <p>“I can't honestly remember. All I remember is that she (the pediatrician) was concerned so I went along with it. I was like, ‘Okay, I don't know. It's my first child. I don't know.’” (CO—English)</p>
Emotions related to identification of a concern	<p>“At first, I was depressed for a long time, and it was hard to get out of it.” (NY—English)</p> <p>“You know, whenever I found out that my son had that problem I cried a lot.” (CO—English)</p> <p>“I used to blame myself. I used to blame myself that I did something wrong.” (NC—English)</p>
Seeking help	
Communication with health care providers	<p>“I had my son evaluated by a specialist.” (NY—English)</p> <p>“I told the doctor and they made [another] appointment.” (NC—Spanish)</p>
Providers: facilitators and difficulties	<p>“Every time I took my children to the doctor's office, I would fill out a questionnaire and sign it.” (NC—Spanish)</p> <p>“She didn't really say anything to scare me. she just asked me questions about what is he doing, how is he doing it, does he struggle to do it. But she's like, ‘Well, you know, it could be nothing, but then again it could be something. Might as well have it checked out.’” (CO—English)</p> <p>“What was nice for me was our pediatrician said, ‘These are the reasons why I'm not worried.’ And that was really helpful. But he said, ‘Since you are, we'll go ahead and do this for you.’” (CO—English)</p> <p>“Her doctor told me to wait, and wait and see how she is doing the following month. And 4 mo passed.”</p> <p>“The doctor kept saying, ‘Oh, he's fine. He'll talk when he wants to.’” (CO—English)</p> <p>“His primary doctor wouldn't [refer him]. He said he was fine.” (NC—English)</p>
Parent action	<p>“I had to change pediatricians. She had a pediatrician from when she was born until 1, and then the other one from 1 to 3. Why would I need a doctor that did not listen to me?” (NC—Spanish)</p> <p>“I went to his doctor. I was crying. I told her, ‘Do not tell me my son is okay. I need something to be done.’ And then she told me, ‘Okay, call this number and [they will] take it from there.’” (CO—English)</p>
Starting services	
Time to diagnosis	<p>“At his 2-yr checkup [I was told] he had a speech delay. [but] that was the problem since he turned 6 mo.” (CO—Spanish)</p> <p>“I still don't actually have a real diagnosis for my daughter. They said she definitely has a developmental delay, they just don't know why.” (CO—Spanish)</p>
Length of time to start services	<p>“I was told there was a waiting list. I didn't want to hear that. I said, ‘I'm really concerned about my [child].’ I really pushed.” (NY—English)</p> <p>“I wish he was diagnosed earlier, from the very first time. Time passed without us knowing. Maybe he could get more therapies. I would have like that.” (NC—Spanish)</p>
Resources	

Theme	Sample Quotation
Sources of information	<p>“Everything that happened to him, I researched it on the Internet and read a lot about why this is happening.” (CO—Spanish)</p> <p>“You can call 311... or go to the library.” (NY—English)</p> <p>“The Head Start Center [helped me].” (NY—Spanish)</p> <p>“And pediatricians. It seems like a lot of them are doing the milestone checks. Which I think is really helpful.” (CO—English)</p> <p>“I found out because I reviewed a flyer from the hospital. The flyer explained what the child should do at 1 yr, 18 mo, and when a child begins to talk.” (NC—Spanish)</p>
Additional resources needed	<p>“I would like to get information. The pediatrician asks about the number of words my child can speak, but I have not seen any information that mentions the number of words children should speak. I did not do anything because I did not have information.” (NC—Spanish)</p> <p>“I think it would be useful to have a phone number to call if you have a question.” (NC— Spanish)</p> <p>“I think it would be a good idea for doctors to be well informed. I think they should be the channel for distributing flyers and information. Because as a mother or a father your first contact person is your doctor.” (NY—Spanish)</p>
Placement and timing	<p>“It would be wonderful for us as mothers, to be educated during pregnancy and then, after the pregnancy.” (NY—Spanish)</p> <p>“It is important to provide information when a child is born, but very often, we put the information away and we never see that again. It would be good that during the different doctor’s appointments, provide information related to the child’s age. For example, in a visit for a 1 yr old, provide information about what to expect when the child turns 2 yr old.” (NC—English)</p>

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 3
In-Depth Interview Themes and Select Quotations

Theme	Sample Quotation
Intended audience and appeal	<p>“I think it helps all parents because we as parents cannot just know what our kids should be doing at certain ages, so this helps us learn more about this. This also helps me in talking to my doctor and asking him questions about my kid and his/her development. It also teaches you things that you can do with your kids in order to test their development and see where they are at.” (NY—Spanish)</p> <p>“[I like] the brochure especially, it’s big and it’s bright, and this is something that I could just tape up to the fridge. So it’s very easy to use, easy to see.”(CO—English)</p>
Purpose and clarity of messages	<p>“Learn the signs” message</p> <p>“[It is asking you] to observe and keep track of your child’s development in a much more knowledgeable and detailed way.” (NY—Spanish)</p> <p>“Because the information, that it breaks it down by age groups and the level where you child should be at. If they’re not there by a certain time, then a good parent is going to start to question, you know, ‘Why isn’t my child doing this?’” (NC—English)</p>
“Act early” message	<p>“[Acting early means] to don’t pass it by, don’t sleep on it. When you see it, don’t just pass it off [saying] ‘Oh, he’ll grow into it’ or ‘They say it is okay.’” (NC — English)</p> <p>“Well, first make sure you go to the pediatrician. Secondly, they give you information you can get on the Internet, which is probably the first thing we would do if we could not see the pediatrician that day. The third thing is to call the 1–800 number.” (CO—Spanish)</p> <p>“What to do if I’m concerned with my child’s development. I didn’t see [it] anywhere.” (CO— English)</p> <p>“Just maybe give a little bit of a reason for [why you should] look for delays.” (CO—English)</p>
Placement and timing	<p>“In the hospital when they’re going to release you. Instead of giving you all the paper and signing all that stuff, I mean, they should give you one of these.” (NY—English)</p> <p>“Because the doctor should know developmental stages. You know they watch your children grow as much as you, so they will have a firsthand knowing where your child should be at this age. If the doctor’s going to give you this information then you’re more prone to trust it.” (NC— English)</p>

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript